Case No: B4/2012/3275

Neutral Citation Number: [2013] EWCA Civ 65

IN THE COURT OF APPEAL (CIVIL DIVISION)
ON APPEAL FROM THE COURT OF PROTECTION
MR JUSTICE PETER JACKSON
COP 12208517

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 1st March 2013

Before:

LORD JUSTICE LAWS
LADY JUSTICE ARDEN
and
THE RT HON. SIR ALAN WARD

- -

Between:

Aintree University Hospitals NHS Foundation Trust	**Appellant**
- and -	
(1) David James (by his litigation friend, the Official Solicitor) **(2) May James** **(3) Julie James**	**Respondents**

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- -

Mr Vikram Sachdeva (instructed by Hill Dickinson LLP) for the appellant
Miss Claire Watson (instructed by Official Solicitors) for the 1st respondent
Mr Ian Wise QC (instructed by Jackson and Canter) for the 2nd and 3rd respondents

Hearing date: 21st December 2012

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Judgment

The Rt Hon. Sir Alan Ward:

Introduction

1. On 6th December 2012 Mr Justice Peter Jackson sitting as a judge of the Court of Protection declared that the first respondent, DJ, who acts by his Litigation Friend, the Official Solicitor, lacked capacity to litigate and to make decisions concerning his medical treatment. There is no appeal against that order. Peter Jackson J also declined to make the declarations sought by the appellant, the hospital treating DJ, that subject to the agreement of his clinical team, it would be lawful, being in his best interests, for the following treatment to be withheld in the event of a clinical deterioration:

   > "• cardiopulmonary resuscitation;
   >
   > • invasive support for circulatory problems;
   >
   > • renal replacement therapy in the event of deterioration in renal function."

   He refused to give permission to the hospital to place a "Do Not Attempt Resuscitation" instruction on DJ's medical records. Permission to appeal was refused by the judge but adjourned to the full court by Munby LJ on 17th December 2012 with the appeal to follow if permission were granted. Given DJ's parlous medical condition, we arranged an urgent hearing and on 21st December 2012, when time did not permit our giving reasons for our judgment, we allowed the appeal and made the declarations sought by the hospital.

2. Sadly DJ died on 31 December and we offer our condolences to his widow and family. We have been asked nevertheless to hand down our judgments and give our reasons for deciding as we did.

3. In this judgment I have referred to the parties by their initials because when the matter was heard, a reporting restriction was in place preserving their anonymity. Since the death of DJ there have been several references to this case in national newspapers and the family have allowed themselves to be identified. In those circumstances it has been agreed that the reporting restriction order made by Peter Jackson J on 27 November 2012 be varied so as to limit protection to the identity of the members of staff of the hospital who were involved in the care and treatment of DJ only. For convenience I shall continue to refer to Mr James, his wife and daughter under their initials.

The sad facts of the case

4. What then are the essential facts of this deeply worrying and unhappy case? DJ was 68 years old when he died. He survived to celebrate the golden wedding anniversary of his marriage to MJ in September 2011. They have three children, their daughter JJ being the third respondent in this appeal. He delighted in his 3 grandchildren. Music has been his life. He was a guitarist and continued to play professionally until his recent illness overtook him.

5. In 2001 he suffered cancer of the colon. He was told it might well kill him but his response was that he would fight it and would beat it. So he did. The tumour was surgically removed and so was the affected part of his colon. He was left with a stoma in the left iliac region, the colostomy bag being fitted on his left side so that he could continue to play his guitar. He also had to undergo the inevitable discomfort of chemotherapy and radiotherapy. The important point from his and the family's perspective is that he overcame the odds and enjoyed more than a decade of happy life thereafter.

6. Unfortunately on 5th May 2012 he was admitted to hospital following 3 days of constipation due to some complication with his stoma. This was soon resolved but while in hospital he acquired an infection that was complicated by the presence of chronic obstructive pulmonary disease, and the development of an acute kidney injury and persistent low blood pressure. On 24th May he became extremely unwell and was admitted to the High Dependency Unit where he was found to have multi-organ failure, with respiratory failure, cardiovascular failure and renal failure. He needed to be intubated and on 27th May was placed on ventilator support in the Critical Care Unit and there he remained.

7. In early June his condition again deteriorated and he again required inotropic drugs for 4 days to restore his blood pressure. This led to necrosis and the consequent blackening of his toes. A tracheostomy was performed on 6th June in an attempt to wean him off ventilator support. This, however, met with only mixed results with his managing from time to time some hours of unsupported breathing but he always returned to the ventilator and he remained fully dependent upon it. On 24th June there was a further diagnosis of hospital-acquired pneumonia and multiple organ failure which needed antibiotics and further inotropic support for 3 days. By now he was developing sacral pressure sores. On 3rd July he suffered septic shock and loss of blood pressure being treated once again with antibiotics and inotropes. There was evidence of acute myocardial infarction. There was deteriorating renal function and

ongoing multiple organ failure. He became unconscious. Tests demonstrated that he had suffered a stroke which left him with right-sided weakness and contracture of his legs which was painful. On 27th July there was a further deterioration and another attack of septicaemia leading once again to more antibiotics, more vasopressors and more ventilatory support. A CT scan showed severe damage to the left side of his brain showing hypoxic ischaemic encephalopathy.

8. By now the pattern was set of tentative recoveries interrupted by recurrent infections leading to lowering of his blood pressure, septic shock and multiple organ failure. Every setback placed him at further disadvantage. He had sadly become a chronic carrier of the pseudomonas organism. As Dr G, the hospital's Consultant in Critical Care Medicine speaking on behalf of the ten consultants and senior nursing staff who were responsible for DJ, explained to the judge in his evidence:

> "400. So we have a condition now with [DJ] whereby he is chronically colonised with pseudomonas, which is well established within the critical care literature as an indication of a very chronic and debilitating condition. It is not amenable to any form of treatment, you cannot give prophylactic antibiotics, i.e. you can't keep giving him antibiotics.
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> 401. Mr Sachdeva [counsel for the hospital]: Why not?
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> 402. Dr G: A) We know it doesn't work. You just can't eradicate it so it's not a medical option at all. It's just not appropriate. But B) all that would do, is again engender a clinical status whereby we are encouraging the multi-organisms that are around in the environment to become more virulent, and we would just create a scenario whereby we would have an organism which would be completely unresponsive to treatment. So by using indiscriminate amounts of antibiotics where they're not clinically indicated, we would not be acting in [DJ's] interests because we would be setting him up and his immunological status up to fail, so it's not an option. So in terms of multiple sepsis episodes, we've got his mechanical status as in his physical environment, his chronic disease process, but also the overall picture is his malnourished state and his complete dependency on

us. That again is an indication of his overall physiological status. He is extremely vulnerable to the external environment."

9. On 13th August DJ had an asystolic cardiac arrest which required Advanced Life Support resuscitation which continued for 6 minutes until the return of spontaneous circulation.

10. On 16th August a worsening of the right-sided hemiplegia was noted with contractures of the legs. Again Dr G explained:

> "299. Dr G: So if I were to give a sort of clinical picture [as of today] I would as critical care specialist look at the whole physiological status. So if I may I would look at first of all his overall, what I would call his clinical state. He is … unfortunately in spite of feeding is chronically and grossly cachetic, which in terms he suffers with extreme muscle wasting due to his chronic dependence on intensive care nursing and other support. So he has huge muscle wasting. As part of that process he also has what we call contractures whereby he has muscle rigidity and that's again due to his chronic critical illness state and unfortunately his inability to respond to physiotherapy. So despite having full and active physiotherapy he has a number of issues with his physical wellbeing.
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> 300. Mr Sachdeva: Well he can't participate actively in physiotherapy?
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> 301. Dr G: No in order we do offer regular critical care physiotherapy which can either be passive i.e. done to the patient. In order for us to gain true rehabilitation it would be extremely beneficial for [DJ] to do what would be active participation and unfortunately because of the nature of both his illness and his neurological status he is unable to work with our physiotherapist. So we do actively attempt rehabilitation but he does not have the capacity to respond to commands and to respond to the physiotherapy request and that would cause considerable concern to us because although this occurs on a regular basis one would assume that if you

> did not have an ability to recognise basic commands, the repetitive motion of physiotherapy would be one which could become, sort of, almost hardwired almost subconsciously. Unfortunately [DJ] is unable to do any of these very repetitive treatments and so the attending team are doing treatments to [DJ] rather than with [DJ]."

11. This pattern continued. On average over this long period he suffered new episodes of infection twice a month, the interval between infections varying between 7 days and 30 days. He suffered acute kidney injuries on 24th May, 4th September and 23rd September. He suffered multi-organ failures (respiratory failure, cardiovascular failure, renal failure) on 27th May, 24th June, 3rd July, 27th July, 13th August, 4th September and 22nd September. Since his cardiac arrest on 13th August he had a further peri-arrest attack that had to be combated with extensive medical support on 22nd October. He suffered a significant deterioration on 19th November when he became very unwell.

12. We admitted fresh evidence of his condition as at 18th December. We were told that he suffered a significant deterioration in his clinical condition on 5th December and became increasingly dependent on mechanical ventilation. He had not managed more than 5 hours of spontaneous breathing since December 5th. Since 14th December he was completely dependent on mechanical ventilation. On 18th December he suffered a further dramatic deterioration which included worsening of his respiratory failure to the point that it was extremely difficult even to achieve good mechanical ventilation. This was accompanied by hypotension which was unresponsive to fluid and required intravenous vasopressors to maintain his blood pressure. He was given a further course of antibiotic therapy. His renal function had also deteriorated. He was at that time comatose or semi-comatose, responding only to painful stimuli by flexing his left arm. We were told:

> "It is likely that this deterioration has been caused by a further episode of chest infection. His chest x-ray series shows a progressive deterioration with extensive changes in both lungs consistent with pulmonary fibrosis or scarring of the lungs on a background of severe emphysema. It is likely that this has resulted from repeated chest infections combined with the effects of prolonged mechanical ventilation …

DJ may or may not survive this acute deterioration in his condition. Even if he does survive this acute episode there remains no realistic prospect of him making sufficient recovery to ever leave the critical care unit let alone making sufficient recovery to be discharged from hospital to go home.

All the clinical team remain convinced that provision of further interventions as listed in the application to the Court of Protection would not be in DJ's best interests and will cause him greater suffering, while conveying extremely limited benefits. Attempting cardiopulmonary resuscitation (CPR) in the setting of this picture of clinical deterioration is highly unlikely to be successful, and in the unlikely event that it is successful it is likely to leave DJ with greater neurological (brain) injury in addition to other organ damage.

In the 11 years I have been a critical care consultant at [this hospital] to my recollection, DJ has been the only patient to stay on the unit for more than 6 months. It is extremely rare for patients to experience such a prolonged stay in a general critical care unit, and when this does happen it is usually in the context of a reversible pathology (i.e. when there is a reasonable prospect of recovery). In most cases of patients with progressive deterioration and such a poor overall prognosis as DJ has, consensus is reached between the clinical team and the family in the best interests of the patient to withdraw or limit organ support intervention. In this case this has not been possible.

Although DJ is currently comatose, or semi comatose, the efforts to support his breathing and blood pressure yesterday clearly caused him great distress and discomfort. Given the extent of the damage to his lungs now it is likely that he will experience frequent sensations of shortness of breath or inability to "catch his breath". He requires frequent (as often as hourly) suctioning of his tracheostomy tube which causes coughing and discomfort. The intravenous vasopressor therapy may cause a feeling of anxiety. While supporting his blood pressure and helping

> perfusion of the kidneys and brain, it is also likely to cause further damage to other tissues and increase strain on the heart. He is extremely weak and unable to move or adjust his own position. He is therefore entirely dependent on nursing staff, even just to turn him or to adjust his position. He cannot communicate in any meaningful way and therefore cannot communicate whether he is uncomfortable at any time, other than by grimacing. This is likely to result in significant periods of discomfort and a feeling of total helplessness. He undergoes regular physiotherapy which he is unable to actively participate in. This causes him discomfort. Hypercalcaemia due to bone demineralisation is associated with bone pain.
>
> It is well documented that patients with critical care illness suffer from disturbing delusions and hallucinations. The incidence of psychological trauma, similar to post-traumatic stress disorder, is estimated to be in excess of 60% in survivors."

13. Once again DJ showed his resilience and great determination to recover. He came out of his coma, and responded to the visits by his family by kissing the hands offered to him. He was a remarkable man. No wonder his family stood so firmly alongside him, encouraging and willing his fight for life.

14. We are now informed that between 21 and 28 December 2012, DJ remained relatively stable and attempts to wean DJ from mechanical ventilation were continued. On 29 December 2012, the clinical team noted signs of sepsis and commenced intravenous antibiotics. As a result of this deterioration, DJ required increased ventilatory support and no further attempts at weaning from mechanical ventilation could be made. On 30 December 2012, DJ showed signs of renal failure and the clinical team initiated a blood transfusion, intravenous fluid resuscitation and diuretics in an attempt to stabilise his condition. Following discussion with DJ's family, circulatory support in the form of metaraminol was commenced. In the early hours of 31 December 2012, DJ suffered a cardiac arrest and sadly passed away. The family were present at the time of death.

15. I would wish to pay my respectful tribute to the family. They won the Court's admiration for the devotion Mrs MJ, her daughter and sons have

showed DJ, visiting him daily and being by his bedside for hour after hour day in and day out since May. Mrs MJ and her daughter travelled to this Court, no doubt at inconvenience, and gave us an invaluable opportunity to hear from them through Mr Wise and to observe their close interest and involvement in the appeal. It must have been a most difficult day for them. Their very presence was a powerful factor in the case ranged against the hospital. Mr Ian Wise Q.C., having taken instructions, told us that Mrs MJ's position was this:

> "1. She wants him to receive such treatment and care as will enable DJ to live as long as and as comfortable a life as possible and to enjoy the love and company of his family.
>
> 2. She would not want to see him suffering or in pain and if she thought he was (but she does not) she would agree to the withdrawal of treatment and to appropriate end of life care."

Mr Wise, like Miss Claire Watson instructed by the Official Solicitor, had little time to prepare for the hearing but I pay tribute to them for the care they took, for the cogency of their submissions and for having done everything that could have been done fully and properly to represent DJ and the family.

16. The judge made these observations about the family's evidence. DJ's daughter felt that although he could not speak because of the tracheostomy, his face was expressive and the family were sure he remained interested in family events, news, music and the radio. That tied in with some evidence from the Official Solicitor's representative who visited DJ. She noted how he held his son's hand, kissed his wife when she leaned into him and continued to watch her as she moved around his bed. When told by a nurse that his wife had telephoned he smiled and made some incomprehensible noises. He smiled and laughed when being sung to and when the nurse asked if he was a good singer, he mouthed "Yes" and nodded his head while laughing. His daughter felt he worried about them and was concerned for her well-being and happiness. She was appalled by the idea of not giving her father treatment. Her goal for her father was for him to recover fully and return home. Asked about the doctors' view that the likelihood of this was less than 1% she referred to the number of other predictions that they had been given: at the end of May the family was told to gather because he was thought to be about to die but he did not and every time he had had an infection he had pulled through. She was convinced that the family would know when the time

had come that it was too much and that resuscitative treatment should cease.

17. Mrs MJ said that her husband had been very alert at a celebration held in September for their golden wedding anniversary. She knew that he would never recover his previous quality of life but felt that he got a lot of enjoyment from seeing his family and also his close friends whom he recognised. She described a recent incident when one of the friends had joked that they could go and have a pint and DJ had pulled his bed sheet back with his hand as if to get up. She felt that his experience of cancer threw light on his values and wishes in the situation in which he found himself. Even though the surgeons had then been pessimistic DJ had never said he had had enough. She and the family believed he would feel the same about his current predicament.

18. The medical evidence was much less optimistic. Dr G said in evidence:

> "372. So I would concur completely with Dr D's statement [Dr D was the Consultant Intensive Care Physician instructed by the Official Solicitor] that [DJ] is in a minimally conscious state but I would also concur strongly with the family's observations that he can have some degree of interaction which is obviously of great benefit to the family. But as a professional that diagnosis has been consistent and there has been absolutely no evidence at any time and I do not project in the future that there would be any evidence to suppose that he would be able to rise from that current status."

Cross-examined he said:

> "573. … If I am asked to give a figure or considered opinion from the critical care consultants that we've got are less than 1% chance of ever getting [DJ] discharged from the critical care unit …
>
> 575. His overall clinical state and the evidence of previous failed attempts so the historical evidence plus his current state, plus our expertise in projecting the future would lead us to the conclusion of his … that our capacity to liberate him from the ventilator is pretty negligible."

19. Mr Sachdeva ended his examination in chief as follows:

> "500. Mr Sachdeva: Just to summarise, if you were told to assume that he gets a great deal of pleasure in his life, the fact that he was a successful musician before, [and that there] isn't any reason to think he doesn't still gain some substantial enjoyment from his current life and that his family, let's just assume for the moment [we] are correct in stating that he would definitely, if he were able to communicate, say that I would really likely to have all the treatment that you can possibly give me. So setting aside the neurological inability to communicate, what effect would that have on your decision as to whether you would offer these treatments in your clinical judgment?
>
> 501. Dr G: It's a question I've considered daily looking after [DJ] and all my colleagues have. We would of course take that matter extremely seriously. It would cause us to have a complete review and consideration of that further information. But if asked that specific question and this is hypothetical, so obviously I am giving an opinion without actually being able to hear that and discuss that directly myself so it would go without doubt that we would take that extremely seriously as the clinical caring team. Notwithstanding all of those, if asked now what my opinion would be, it would still be that the treatment we are proposing would be inappropriate and I would be explaining that and my rationale to [DJ] and explaining why I thought it would be deeply inappropriate for me as the attending clinician and the rest of my colleagues to offer these treatments, so I would go through that process that we have undergone now to explain why I would say that to another human being. It would be my professional obligation to do that and my professional opinion would still stand that the types of, and the proposed treatment that me and my colleagues feel is the right course of medical action to take would still stand."

The treatment DJ was being given and the treatment the hospital wished not to give him

20. At the time of the hearing before us, DJ was receiving and we were assured would continue to receive a high level of medical support including ventilation to allow him to breathe. There was no suggestion that this extensive base line treatment should be stopped. Nor was there then any suggestion that the treatment should move onto the so-called Liverpool Care Pathway which is a protocol that has been developed to treat those who are near death in a way which gives them as little distress and as much dignity as possible by means of a humane and carefully controlled withdrawal of treatment. The family believed that DJ has been placed on the Pathway. The doctors were absolutely clear that this was not the case. The judge held, and it is important to reinforce this finding:

> "12. … I entirely accept their evidence about this. DJ is not and has never been on the Liverpool Care Pathway.
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> 13. This application is not about the standard of care DJ is receiving. Nonetheless, I record that the evidence shows that he has received a high quality of care during his time in hospital and that the staff are devoted to looking after him to the best of their ability."

21. When the hospital launched this application, the critical care team sought permission not to administer intravenous antibiotics to treat further infectious complications. The hospital did not pursue that application. When DJ suffered the further dramatic deterioration on 18th December, he was treated with a further course of antibiotic therapy. It was, however, the hospital's firmly held opinion that it was not in the best interests of DJ to administer invasive support for circulatory problems or renal replacement therapy in the event of a deterioration in renal function or to administer cardiopulmonary resuscitation. Dr G gave evidence of what was involved in those treatments which I shall recite at length because it is of crucial importance to the conclusion at which we arrived.

22. When Dr G was invited to deal with the three forms of treatment which were the subject of the application, they happened to be put to him by Mr Sachdeva in the order of CPR, invasive support for circulatory problems and renal replacement therapy. But Dr G began by saying:

> "415. Dr G: If I may I would leave this cardiopulmonary resuscitation to the … as the final one because there's a, in my opinion, a logical sequence of clinical decision making process.

416. Mr Justice Jackson: Well let's reverse them in that way, how would you start?

417. Dr G: Sir, I would start with what has been the consistent pattern of deterioration, both with [DJ] and with a wider critical care patient which would be a septic episode so an infection of some sort, whether it be a bacteria or virus, and often we don't ever determine what is the causative factor because for obvious reasons, we don't wait and it's not always possible technically to determine what the specific organism is. But nevertheless, if we see signs of low blood pressure, high heart rates and low urine output with other signs of temperatures and blood tests and so on, we can make a clinical diagnosis of sepsis. In my opinion and in the consensus of opinion of all ten critical care consultants, in [DJ's] case he doesn't respond to fluid, so the fluid (inaudible) has been given which are very rapid administration of fluid above and beyond what he is currently getting as baseline. If he doesn't respond to that or can't respond to that, it'd perhaps be the better phrase and then we have persistent low blood pressure which would then, by definition, cause further consequences. What we would consider at that point is would we or should we offer the … well we are terming it invasive circulatory support. In my opinion and in the consensus opinion of my colleagues, in order to do that we would have to weigh up all the other issues that we've alluded to before, we would have to put in a very large drip, similar to the one we needed to renal replacement therapy. You can give treatment through smaller drips, but again that is sub-optimal and again we have to look at the overall picture and there may be a technical possibility of us doing that but we'd have to make a decision based on that as what was our intended consequences. So we'd start off with that form, would we do or should we do that.

…

421. We are attempting to restore normal blood pressure, normal oxygen levels to all the peripheries and to all the vital organs.

…

425. We are delivering very potent drugs, which the medical term can include vasopressors and inotropes, quite often when we talk to relatives we use the words drugs such as adrenaline …

427. This can narrow the blood vessels, it can tighten them up. So what we would suggest it would do is it would decrease the calibre of the vessels within the body and it can increase the functionality of the heart. It will make the pump work better so the heart works as a more efficient pump and it can increase the rate at which the heart works. So not only will it function better, it will work quicker. They are the intended benefits of such a drug, they have very severe negative or potentially negative consequences which is why they are drugs which can only be used in a … by critically care trained nurses and doctors and usually only exclusively in an environment that is able to support that so classically only in a critical care environment.

…

441. Mr Sachdeva: What are the negative consequences of using vasopressors and inotropes?

442. Dr G: There's the I suppose inappropriate perhaps use of the word aggressive. The way we use it is a technical process of subjecting a human being to discomforting pain with needles. That's the clear one, it's the smaller ones in the limbs are painful and like having any form of blood test, the larger bore devices we need to use … we sometimes call them central lines, but the lines that he uses to provide either kidney support or indeed very invasive blood pressure. But the central lines are very discomforting, they require or usually require the administration of a large amount of local anaesthetic because they are extremely painful to [introduce]. There's a large number of technical challenges in patients who are malnourished, who've had lots of previous attempts, the technical challenges become more and more

cumulative because the vessels themselves become blocked. They become potentially infected, the skin gets … there are obviously holes for the needle itself and there are also the requirement for us to put sutures, stitches to secure the device. There's a requirement of constant dressing, just the sort of basic housekeeping of tending these lines is pretty distressing. …

445. Mr Sachdeva: Is there more strain on the heart?

446. Dr G: There is indeed, there are very significant deleterious effects indeed when you can cause arrhythmias so you can put the heart into abnormal pacing. You can cause the heart itself to have very serious consequences from very fast rates to actual rates that are not compatible with life. It is very well recognised that these treatments can cause the heart to do this.

447. Mr Sachdeva: 13th August he had asystotlic cardiac arrest having had vasopressors. Do you think there's a link there?

448. Dr G: At the time I'd have been unable … I would've have been unable to … I don't know.

449. Mr Sachdeva: Is it possible?

450. Dr G: It is possible. We see very regularly with very potent drugs such as adrenaline, raw adrenaline that it does sensitise the heart to abnormal rhythms and in the heart stops. The other consequences are, as indeed DJ's case, as we are tightening the calibre of the blood vessels in order to sort of preserve function to the very delicate organs as in the kidney, what we do is we ask the body to by-pass the peripheries and [DJ] has necrotic toes, he has a number of black toes which are as a result arguably or actually probably very consistently of the treatment that we've administered to him. He's got black toes which are a very clear and visible reminder to me, as a clinician who cares for him, of the negative effects of the treatment that I would offer a patient."

23. Dealing with the diagnosis of kidney failure, Dr G said this:

> "324. My guess would be that his kidney reserve is no more than that [he has got 20% kidney functioning]. It's extremely low, difficult to give a specific percentage but we know that the blood tests when they do show damage not just showing beginnings they're sort of at an end stage of process.
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> …
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> 328. [Sepsis] consistently, repeatedly removes that reserve until there is no reserve, so the inevitability will be that chronic multiple sepsis episodes will lead to a likely chronic dependence on kidney support so we will see, unfortunately, if further episodes do occur a repeated and inevitable decline in kidney function.
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> …
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> 332. We performed a form of renal support that is only suitable in the short term. There is a form of renal support, the dialysis which is more for an outpatient long term condition.
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> …
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> 339. Mr Justice Jackson: And this is a large tube?
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> 340. Dr G: It is indeed. It's a very large bore tube which is technically difficult to place and it has to go in one of the large veins in the body so either in the neck, below the collar bone or at the top of the groin. There are only 6 sites where one can technically insert this device."

24. Asked whether there were any negative aspects or suffering that would be experienced in having renal replacement therapy, Dr G answered:

> "452. In addition to the sort of challenges that we've already discussed, renal replacement therapy requires the blood to be thin. As the blood is processed through an artificial … I guess an artificial kidney, it needs to be thinned otherwise the blood will clot and the machine will not work. In order to administer a

constant blood thinning medication, we have to do repeated blood tests, that's in order to make sure we've got the level appropriate.

453. Mr Sachdeva: Is that warfarin or?

454. Dr G: It's similar, it's a drug called Heparin and it needs to be given as a constant infusion, requires some careful titration because there is significant and very real risk of bleeds. So that can be bleeding from where we've actually just put the large bore canula in, but in particular, in our critically ill patients bleeds from a stroke point of view.

455. Mr Sachdeva: He's had an ischaemic stroke before?

456. Dr G: He has indeed.

457. Mr Sachdeva: This might give rise, I suppose to a haemorrhagic type of stroke?

458. Dr G: There are a number of different causative pathways for a stroke and one of those we consider when we're balancing the risks and benefits, is the possibility of a bleed type stroke, as you say a haemorrhagic stroke. And also within a critically ill population, they are extremely prone to bleeding from the digestive tract so he's on constant medication to try and limit the possibility of a bleed from the GI tract, i.e. an ulcer or an erosion within the stomach or … something within the stomach or gullet. One of our concerns would be that blood thinning medication could precipitate that as a type of adverse consequence, and I guess the one that I would be personally really concerned about would be that the temperature imbalance that is caused by putting somebody on renal replacement therapy in essence because you are taking a large amount of our patient's circulating volume to the external environment and then returning it. What we see very commonly is a shivering or cold response, that is one we try and mitigate against but we see very frequently so we induce a very unpleasant experience. Indeed we just

… we make patients shiver and make them feel very cold.

459. Mr Sachdeva: Well what would it be like? How cold would one feel? Have you any sense?

460. Dr G: Cold enough to at least say … you know a form of shaking response. So if you were to see a member of the public who is out and who is exhibiting you know clear distress from cold, shaking and so on.

461. Mr Sachdeva: How long would it go on?

462. Dr G: For the duration of therapy.

463. Mr Sachdeva: Which is how long?

464. Dr G: We use renal patient therapy usually in excess of sort of 8-12 hours would be a short course normally. It would be on average about sort of 24 hours course.

465. Mr Sachdeva: And they'd shiver throughout the 24 hours?

456. Dr G: They can.

467. Mr Justice Jackson: When you say a course, this is 24 hours for example in a row?

468. Dr G: It will be 24 hours then a response, yeah, it's likely when you usually and I suppose I shouldn't have used … in the terms with [DJ], if we are in a position of needing renal replacement therapy, it would be highly unlikely to project this would be short course. It would highly likely because … because as discussed of his very minimal reserve, once he became … once he knew it was renal replacement therapy, there was a high likelihood it would become a dependency state.

469. Mr Justice Jackson: So although it wouldn't be identical by the manner of means in its delivery and so forth it would be rather like ventilator equation?

470. Dr G: That would be my clinical assessment.

471. Mr Sachdeva: He might need it continuously?

472. Dr G: That would be a very likely clinical scenario. It's highly likely that …

473. Mr Sachdeva: He is very likely to need?

474. Dr G: Very likely if the treatment is required it would be … it would be difficult to see the scenario whereby it would be a one-off form of treatment given the overall clinical trajectory of [DJ's] care over the last 5 months.

475. Mr Sachdeva: Once he had been on it there would be no way of taking him off it if his kidneys weren't themselves functioning well enough?

476. Dr G: We would make a … it would be judged on the clinical context obviously but the overall clinical scenario in my opinion would be that once … once we had requirements for renal replacement therapy, it would inevitably lead to a state of chronic dependency on that form of support."

25. Dealing with cardiopulmonary resuscitation he said:

"478. The way I process the risks and benefits would be to suggest that if the treatment as described, so the blood pressure would deteriorate that would require invasive circulatory support which would then cause renal failure which would then require renal replacement therapy. If in my clinical opinion that was treatment that would not be indicated, it would then, in my mind be clear to see a continued deterioration of the patient that resulted in their heart stopping. If we got to that scenario, it would then seem to me very clearly and in appropriate [sic I think the transcript should read "very clearly an inappropriate"] decision to offer active resuscitation. And my clinical rationale would be that if while a patient is deteriorating but the heart hadn't stopped, we thought it was inappropriate to offer this form of therapy because it was not going to be of overall benefit to the patient. Then it would seem completely incongruous then to offer very aggressive therapy.

…

484. … the literature would very clearly state that patients who had not regained their normal function status and who have continued to be critically ill, the continued trend would be that even if we were to offer cardiopulmonary resuscitation, the chances of successful resuscitation are diminishing each day as he remains critically ill. So in my opinion, not only would be it be highly unlikely to be successful, it would also not be an appropriate course of treatment as we would not deem the … what I would call the preceding forms of treatment I would normally consider for a patient, i.e. in the case of cardio support and the renal support. If we weren't considering those options to then do a cardiopulmonary resuscitation, would seem a medically incompatible decision process.

485. Mr Sachdeva: Assuming that the other two were to be thought appropriate, CPR is a further step.

486. It is a further step and in patients who are on critical care and we are assuming that a patient or indeed [DJ] is on invasive circulatory support, he's on renal replacement therapy. If they do suffer cardiopulmonary resuscitation the success rates are almost negligible that the decision making process we … it would be difficult to envisage a scenario where we would actively offer that as a form of treatment. And indeed … the act of performing cardiopulmonary resuscitation is one which is deeply physical, it involves the compression of the human chest by a skilled healthcare professional. The force of the compression in a significant number of cases causes rib fractures, part of the resuscitation process that involves manually inflating the lungs using essentially a very crude but very skilled process of forcing air into a human's lungs and administration of a drug similar to adrenalin, would be the standard care.

487. Mr Justice Jackson: Administered how?

…

490. Ideally it would be administered by intravenous access so we would need to gain access which would be technically very difficult if it wasn't already in place. One can in theory give the drug down the breathing tube although that is far from effective and not necessarily recommended really, but if we were to offer this with the intention … with the right intention which is to do it to our best clinical capacity we would have to attempt to gain access which would be … which would likely be very challenging given the crisis nature of this condition.

491. Mr Justice Jackson: What is the sort of time period typically that that decision might have to be made within?

492. It would have to be done instantaneously, if it's not a cardiac arrest situation is a medical emergency. There is no time here, indeed the time is of the essence. If we are unable to gain IV access, if we are unable to restore the heart, the progressive nature of the heart stopping means the longer it takes before the heart starts the less likely it is to start.

493. Mr Justice Jackson: Are we talking about seconds or a minute or two?

494. Dr G: Yes my Lord.

…

496. Mr Sachdeva: I've just one further question. Is there anything else unpleasant from the person's perspective about CPR apart from compressions and the adrenaline? You're shocked sometimes.

495. You're shocked, so depending on the nature and if the heart either stops in terms of no recordable electrical activity, or there are scenarios whereby there is electrical activity but it's not compatible with life. In the second scenario we administer electric therapy. We place very large pads on the chest of our patients and we administer direct electrical currents which causes … or the intention is to cause a re-boost, almost like a reprogramming of the heart's electrical

> activity. But obviously it causes the whole body to be subject to that electrical activity which … it's clear to anybody attending is a very … potentially a very distressing thing to administer."

26. I have recited this evidence at length, perhaps at too great a length, but the evidence was not challenged and was rightly accepted by the judge. It is important, in my judgment, to see the whole picture and to give the family cause to reflect on exactly what would have been involved in taking these steps.

The judgment under appeal

27. The judge correctly directed himself that pursuant to s. 1(5) of the Mental Capacity Act 2005,

> "An act, or decision made, under this Act for or on behalf of the person who lacks capacity must be done, or made, in his best interests."

S. 4 of the Act gave some help in relation to the factors to be taken into consideration when assessing best interests and he reminded himself of these subsections:

> "4(2) The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.
>
> (3) He must consider-
>
> (a) whether it is likely that the person will at some time have capacity in relation to the matter in question, and
>
> (b) if it appears likely that he will, when that is likely to be.
>
> (4) He must, so far as is reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.
>
> (5) Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person

concerned, be motivated by a desire to bring about his death.

(6) He must consider, so far as is reasonably ascertainable –

(a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),

(b) the beliefs and values that would be likely to influence his decision if he had capacity, and

(c) the other factors that he would be likely to consider if he were able to do so.

(7) He must take into account, if it is practicable and appropriate to consult them, the views of –

(a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,

(b) anyone engaged in caring for the person or interested in his welfare, …

as to what would be in the person's best interests and in particular as to the matters mentioned in ss (6).

…

(10) "Life-sustaining treatment" means treatment which in the view of a person providing health care for the person concerned is necessary to sustain life.

(11) "Relevant circumstances" are those-

(a) of which the person making the determination is aware, and

(b) which it would be reasonable to regard as relevant."

28. Under s. 42(1)(b) the Lord Chancellor must prepare and issue one or more codes of practice for the guidance of persons acting in connection with the care and treatment of another person and ss (5) requires that if it

appears to a court that a provision of a code is relevant to a question arising in the proceedings, the provision or failure must be taken into account in deciding the question. Paragraph 5.31 of the Mental Capacity Act Code of Practice provides relevant guidance:

> "All reasonable steps which are in the person's best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the person's death. The decision-maker must make a decision based on the best interests of the person who lacks capacity. They must not be motivated by a desire to bring about the person's death for whatever reason, even if this is from a sense of compassion. Healthcare and social care staff should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment."

The judge held:

> "74. I consider that this is an accurate statement and that one central question in the overall assessment of best interests is whether this is one of the limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery."

29. In his "Discussion and Conclusions" the judge said:

> "81. In relation to DJ's medical condition and his prospects, the experience of the doctors is persuasive. The family's hope is for a miracle, but where medical matters are concerned, the court must have regard to the unanimous expert advice. In particular, the evidence of the burdens of this kind of treatment must carry heavy weight.
>
> 82. Even so, that advice is bound to be based on an assessment of probabilities, and there will be a very

> small number of cases where the improbable occurs. Moreover, the assessment of best interests of course encompasses all factors of all kinds, and not medical factors alone, and reaches into areas where doctors are not experts.
>
> 83. In considering this matter, I have tried to guard against an unduly rosy overall assessment arising from the fact that DJ appears to be doing reasonably well at present, or to over-interpret his abilities or overstate his potential. It is necessary to assess the situation as whole, and also to take one's thoughts to a time of acute deterioration, when the question would be whether treatment would be worthwhile in order to restore DJ to his current quality of life, at best, and very likely not even to that level."

30. Having weighed all those matters, the judge reached "the clear conclusion that it would not be appropriate at this time to make the declarations that are sought". He gave these reasons:

> "84(1). Although DJ's condition is in many respects grim, I am not persuaded that treatment would be futile or overly burdensome, or that there is no prospect of recovery.
>
> (a) In DJ's case the treatments in question cannot be said to be futile, based on the evidence of their effect so far.
>
> (b) Nor can they be said to be futile in the sense that they could only return DJ to a quality of life that is not worth living.
>
> (c) Although the burdens of treatment are very great indeed, they have to be weighed against the benefits of a continued existence.
>
> (d) Nor can it be said that there is no prospect of recovery: recovery does not mean a return to full health, but a resumption of a quality of life that DJ would regard as worthwhile. The references, noted above, to a cure or to a return to the former pleasures of life set the standard unduly high.

(2) I consider that the argument in favour of a declaration significantly undervalues the non-medical aspects of DJ's situation at this time. These arguments would undoubtedly carry the day in a case where quality of life was truly awful or non-existent. I cannot find that this is the situation that DJ is in, looking overall at the peaks and troughs and the likely future deteriorations. Moreover, as Hedley J put it in *NHS v Baby X* [2012] EWHC 2188 (Fam) a life from which others may recoil can yet be precious. It may be of some note that counsel were not able to identify at short notice a case in which the withholding of treatment has been approved in a case where the patient's quality of life was comparable to DJ's and where the family was in such clear opposition. In this case, DJ's family life is of the closest and most meaningful kind that carries great weight in my assessment.

(3) Care must be taken in making declarations in circumstances that are not fully predictable or are, as here, fluctuating. Making full allowance for the unpleasant, painful and distressing aspect of treatment, I cannot conclude that it would be right to validate, in advance, the withholding of any of these treatments in all circumstances.

(4) I have balanced the various rights enjoyed by DJ and his family in reaching a conclusion: these encompass articles 2, 3 and 8 of the European Convention on Human Rights.

85. I emphasise that this decision goes no further than to say that this court is not persuaded on the evidence before it that the withholding of these treatments is in DJ's best interests. I likewise emphasise that I am not deciding that the treatments must be offered. Not only is that not the court's place, but it does not have the evidence on which to reach that conclusion.

86. The outcome therefore is that DJ will continue to be cared for by his medical carers and by his family, who will have to discuss between them the issues that arise at the time that they arise. If there is another

> crisis, the doctors and the family will have to try to reach a common view. It may be that this will involve treatment of one kind or another; it may be that the family will agree that DJ has had enough. The matter will have to be discussed, and there is no easy answer. I recognise that this arrangement does not sit easily with the emergency decision about CPR, and for what it is worth I think it unlikely that further CPR would be in DJ's best interests. However, the case for making that an absolute decision at this time does not in my view arise."

31. The judge ended his judgment, and I echo his sentiments, by saying:

> "88. I end by paying tribute to the extremely skilful professional care that DJ has received from his doctors, nurses and other medical staff, and to the steadfast love and commitment of his family in his time of trouble."

32. The appellant alleges that the judge erred in:

(1) Having found that receiving further CPR was not in DJ's best interests, failing to grant a declaration to that effect.

(2) Applying a test requiring the quality of life to be "truly awful or non-existent".

(3) Eliding the test of best interests being futile, overly burdensome and/or there being no prospect of recovery.

(4) Failing to find that the treatments were futile, overly burdensome and that there was no realistic prospect of recovery.

(5) Placing decisive weight on the family's evidence of DJ's likely views.

(6) Finding the pre-condition of there being "a significant clinical deterioration" to be too uncertain to justify declarations being made.

Discussion

33. The judge's first reason for refusing the declarations is set out in [84](1) where he considered the guidance in the Code of Practice. He had described that at [74] to be an accurate statement and had directed himself that "one central question in the overall assessment of best interests is

whether this is one of the limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery". Mr Sachdeva for the hospital criticises the judge in ground 3 for eliding the test of best interests with the concept of the futility etc of the treatment. He submits that the test is simply what is in the best interests of the patient. I agree. That is plain from s. 1(5) of the Act. Decisions must be made for or on behalf of a person who lacks capacity in his best interests. That is the one and only ultimate test. I do not, however, accept the criticism made of the judge that he had allowed his conclusions on futility etc to govern his decision. Paragraph [74] of his judgment makes it plain that the guidance is one, not *the one and only,* central question in an overall assessment of where best interests lies.

34. For me the real question in this appeal is whether the judge correctly applied the guidance and whether he was right to find that the treatments in question could not be said to be futile. He reached that conclusion based "on the evidence of their effect so far". He was judging the worthwhileness of these treatments by the success they had had when given to DJ on previous occasions when he needed that treatment. As the most obvious example, he suffered a cardiac arrest, his heart had stopped, he had cardiopulmonary resuscitation, his heart started beating again and he recovered. So the judge reasoned that CPR was successful; it was not futile; and it would not be futile if it had to be undertaken again. Assuming, for present purposes, that future treatment would indeed be successful and that it would not, therefore, be futile in that sense, the real question that arises in this appeal is whether the judge erred in law in giving the concept of futility the meaning he ascribed to it.

35. In my judgment to answer the question whether the proposed treatment would be futile one has to ask what result the treatment seeks to produce. Futility is an ethically controversial concept because what is worthwhile can only be assessed relative to its goal. Thus the crucial question is to determine what the proper goal is for life-sustaining treatment, defined in s. 4(10) of the Act to be "treatment which in the view of the person providing healthcare for the person concerned" (and by necessary extension, the view of the court which is called upon to sanction that treatment) "is necessary to sustain life." The goal can be stated in one, or perhaps more than one, of these ways:

(1) The goal may be to prevent the patient's imminent death from the particular ailment which the treatment is designed to overcome (to give again an example in crude and unscientific terms, CPR is necessary and effective in the case of a heart attack to get the heart beating again).

(2) Having prevented imminent death, the goal may be to prolong life even though it is recognised that it will be for a relatively brief time only.

(3) The goal may be to delay death even though it will not result in any significant alleviation of the patient's suffering.

(4) The goal may be to provide for the patient a minimum quality of life for the remainder of his life.

(5) The goal may be to allow the patient to achieve the goal (or the wish) he has set for himself.

(6) The goal may be to secure therapeutic benefit for the patient, that is to say the treatment must, standing alone or with other medical care, have the real prospect of curing or at least palliating the life threatening disease or illness from which the patient is suffering.

36. I do not see that futility should be judged simply by the ability to score goals (1)-(3). There is no duty to maintain the life of a patient at all costs. There is no duty needlessly to prolong dying. Even John Keown, who with John Finnis believes that human life is itself a basic intrinsic good, does not support the "vitalist" view that regardless of the pain and suffering that life-prolonging treatment entails, it must be administered since human life is to be preserved at all costs. As for the fourth goal, it is difficult to deny that there is implicit in every judgment about whether treatment is futile or worthwhile a judgment about the quality of life the patient will have with or without that treatment. Like it or not lurking within the question or perhaps behind it is the ethically controversial question: is it worthwhile keeping this patient alive? I will deal with that later. The fifth goal raises a question which cannot be avoided when considering the best interests of the patient, namely, what does the patient wish for himself. But the patient's wishes are not the deciding factor in working out his best interests and do not determine what treatment he should receive. The patient's own wishes have a part to play, as I shall show, in the final question of what is in his best interests but his wishes do not dictate what is in his best *medical* interests.

37. My judgment is that the futility of treatment must be judged in the light of the answer to the sixth question I posed in the preceding paragraphs. This happens to accord with John Keown's view that the right question to ask in these end-of-life decisions is whether the treatment is worthwhile in the sense that it will bring therapeutic benefit to the patient. It accords with *Mason & McCall Smith's Law and Medical Ethics* 8th ed. view that, "We much prefer to speak of non-productive treatment, which places the

problem firmly in the medical field …": see their discussion at paragraphs 14.04 to 14.06. It coincides with the definition preferred in the 3rd edition of what started as Kennedy & Grubb's *Principles of Medical Law* at 10.214: "Treatment can properly be categorised as futile if it cannot cure or palliate the disease or illness from which the patient is suffering and thus serves no therapeutic purpose of any kind."

38. It follows that in my judgment the judge erred in law in adopting too narrow a view of futility. He was wrong simply to look at the past successful effect of the treatment without also having regard to the improvement, or lack of improvement, that such treatment will bring to the general health of the patient. He was wrong to concentrate on the usefulness of the treatment in coping with the crisis and curing the disease or illness, e.g. the cardiac arrest, and not also to be concerned instead with whether the treatment was worthwhile in the interests of the general well-being and overall health of the patient. The narrowness of the judge's focus undermines his judgment and I would allow the appeal on that basis alone.

39. There is a further point which forms the first ground of the appellant's appeal. Having found in paragraph [84](1) that all the treatments, including CPR could not have been said to be futile, he went on in [86] to deal with what should happen "if there is another crisis". That, of course, is precisely what he was being asked to consider in this case: the hospital were postulating the probability of another crisis and asking whether, if and when that occurred, they would need to apply treatment including, if it were called for, cardiopulmonary resuscitation. The judge found that in the event of an emergency decision about CPR it was unlikely that CPR would be in DJ's best interests. That conclusion in [86] conflicts with his conclusion at [84](1)(a). Considering what should happen in the emergency was the decision he was called upon to make and he was wrong to say that the case for making that decision at the time he gave his judgment did not exist. This is a further reason for allowing the appeal.

40. The fourth ground of appeal challenges the judge's findings that the treatments were not futile, overly burdensome and that there was a realistic prospect of recovery. I am driven to say that, with respect to the judge who has considerable experience in this field, I cannot accept that the three forms of treatment were not overly burdensome. I take full account of the fact that the judge heard the evidence but since that evidence was not challenged, this Court is in as good a position as the judge to draw inferences from the primary facts that were there established. I appreciate also that this Court should not lightly interfere with an exercise of discretion, or more accurately an evaluative judgment,

unless it is outside the generous ambit within which there is reasonable room for disagreement. Here the evidence seems to me to be overwhelming.

41. To restore falling blood pressure the medical team would have to put in a very large drip similar to the one needed for renal replacement therapy. They would have to deliver very potent drugs, vasopressors and inotropes, through those central lines. At [442] of his evidence Dr G described them as "very discomforting, they require or usually require the administration of a large amount of local anaesthetic because they are extremely painful to introduce." They produce more strain on the heart and there are (see [446]) "very significant deleterious effects indeed when you can cause arrhythmias … cause the heart itself to have very serious consequences from very fast rates to actual rates that are not compatible with life." It may be that this is what led to the fatal heart attack. He had not excluded the possibility that earlier invasive circulatory support had caused the cardiac arrest from which he subsequently suffered.

42. Dr G also explained the burdens of renal replacement therapy. Again it involved the placement of a large bore tube to administer blood thinning drugs which carried the risk of the patient suffering a stroke. There was a risk of bleeding within the stomach or gullet. But the problem with which Dr G was "personally really concerned" was the temperature imbalance that left the patient cold and shivering for the duration of the therapy which on average was a 24 hour course. The really serious burden to my mind was that, given his very minimal renal reserves, once he started renal replacement therapy, "there was a high likelihood it would become a dependency state," (see [468] and [476]).

43. The burden of CPR is that the resuscitation process involves manually inflating the lungs and the force of the compression in a significant number of cases causes rib fractures. We had to bear in mind the frailty of this malnourished patient and in particular the loss of bone density which made fractures of the ribs more likely.

44. When it comes to a consideration of whether or not there was a prospect of recovery the judge held at [84](1)(d) that "recovery does not mean a return to full health, but a resumption of a quality of life that DJ would regard as worthwhile." Once again I respectfully conclude that the judge has applied the wrong test when considering the guidance in the Code of Practice. As I have indicated in my discussion on the meaning of futility, what the guidance is concerned with is answering the question, "how should someone's best interests be worked out when making decisions about life-sustaining treatment?" As is stated at 5.30:

> "It is up to the doctor or healthcare professional providing treatment to assess whether the treatment is life-sustaining in each particular situation."

In other words the focus is on the medical interests of the patient when treatment is being considered to sustain life. That is not to say the doctors determine the outcome for it is the court that must decide where there is a dispute about it and the court will always scrutinise the medical evidence with scrupulous care. Here we were necessarily dealing with a situation where life was ebbing away. In the context, therefore, "no prospect of recovery" means no prospect of recovering such a state of good health as will avert the looming prospect of death if the life-sustaining treatment is given. DJ had a less than 1% chance of ever being released from the intensive care unit. He was slowly dying, not "actively dying", as clinicians might describe his state had he been in such a condition that the Liverpool Care Pathway might have become appropriate. But there was no prospect whatever for this unfortunate brave man ever overcoming the multiple organ failure from which he had suffered with exponentially weaker prospects of recovery. This is a further reason for allowing the appeal.

45. Having allowed the appeal, it is open to us to form our own judgment of what is in the best interests of DJ. The fact that I have concluded that treatment would be futile, overly burdensome and that there is no prospect of recovery is but one pointer to where the best interests of DJ lie. Not to treat him may be in his best *medical* interests but the question remains whether it is in his best interests overall and here I have to accept that "the term "best interests" encompasses medical, emotional, and all other welfare issues" – see Wall LJ in *Portsmouth Hospitals NHS Trust v Wyatt* [2005] EWCA Civ 1181 [2005] 1 WLR 3995 at [87] following *In Re A* [2000] 1 FLR 549. It may not be possible to attempt to define what is in the best interests of a patient by a single test applicable in all circumstances – see Lord Philips of Worth Matravers MR in *Burke's* case at [63] – but some help is given by the Mental Capacity Act itself. The court must pursuant to s. 4(6) consider, so far as is reasonably ascertainable, the person's past and present wishes and feelings, his beliefs and values and the other factors he would be likely to consider if he were able to do so. The court must take into account the views of those caring for DJ as to what would be in his best interest and particularly what they consider to be his real wishes and feelings. It was common ground, as recorded in the judgment at [79] that:

> "• Life itself is of value and treatment may lengthen DJ's life.

> • He currently has a measurable quality of life from which he gains pleasure. Although his condition fluctuates, there have been improvements as well as deteriorations.
>
> • It is likely that DJ would want treatment up to the point where it became hopeless.
>
> • His family strongly believes that this point has not been reached."

Against that background, what conclusions can be drawn about DJ's wishes and feelings and particularly his wishes and feelings as to whether he should be given life sustaining treatment in the condition he is in?

46. It can be safely said that DJ was showing the same strength, courage and willpower to overcome the afflictions which beset him as he showed when he was fighting and defeating his cancer. He then won against the odds and apparently against the pessimistic advice he was then being given. His wish was to do so again. Because of his love for his family and the pleasure he derived from them he wished to live as long as he could. This is echoed by Mrs MJ – see [14] above where her position was so clearly stated by Mr Wise. It may, therefore, be said that for his emotional wellbeing treatment should be continued.

47. In my judgment, however, this is too limited a view. The court has to endeavour to ascertain his wishes and feelings, so far as they are reasonably ascertainable. And in this case his lack of capacity prevents the medical team engaging with him in any discussion about future treatment. So the court has to have regard to the factors that he would be likely to consider if he were able to do so. Those factors would include facing up to the virtual certainty that he would never leave the critical care unit, never be free of dependence on his ventilator but would always be subject to recurring infections where, as was common ground and recorded at [79] "every setback places him at a further disadvantage." The harsh reality, so harsh that it was understandably impossible for the family to accept it, was that his position was hopeless. His wishes, if they were to be the product of full informed thought, would have to recognise the futility of treatment, that treatment would be extremely burdensome to endure, and that he would never recover enough to go home. All this would be extremely distressing for his family. One is driven to conclude that his wish to survive was unattainable. Miracles may happen but on the facts of this case the probabilities were overwhelming against a miracle happening in this case. We had to act on the real possibilities not

those which were fanciful. In the overall assessment, therefore, of where his best interests lie, I respect his wishes but in my judgment they must give way to what is best in his medical interests.

48. How does "quality of life" fit into this analysis? There is deep academic controversy about this question. We have not had argument addressed to it and we are expressly asked by the respondents not to trespass unnecessarily. What follows is therefore to be treated with caution but it seems to me that something should be said about this. There are essentially two schools of thought. One is championed by John Finnis, Luke Gormally and John Keown. In his most recent work on the subject, *The Law and Ethics of Medicine* published in August 2012, John Keown writes at p. 5:

> "Human life is a *basic, intrinsic* good. All human beings possess, in view of their common humanity an inherent, inalienable, and ineliminable dignity. …
>
> To sum up, the doctrine of the IOL (the Inviolability of Life) holds that we all share, in virtue of our common humanity, an ineliminable dignity. This dignity grounds our "right to life". The principle of the IOL holds in essence that it is wrong to try to extinguish life."

His theory is that:

> "The IOL distinguishes what we may call "quality of life benefits" (used to judge whether a treatment would be worthwhile, comparing its benefits and burdens) from "beneficial Quality of life" (QOL) used to judge whether a patient's life is or will be "worthwhile"."

He defines "Quality of life" (QOL) in this way:

> "On this approach, there is nothing supremely or even inherently valuable about the life of a human being. The dignity of human life, such as it is, is only an *instrumental* good, a vehicle or platform for a "worthwhile" life, a life in whose value resides in meeting a particular "quality" threshold (howsoever defined). The lives of certain patients fall below this threshold, not least because of disease, injury or disability. This valuation of human life grounds the

> principle that, because certain lives are not worth living, it is right intentionally to terminate them, whether by act or omission. A core principle, therefore, is: "One may try to extinguish the life of a patient which is of such poor quality as not to be worth living"."

That QOL approach may, or may not, be an entirely fair way of putting the opposite view which is held particularly by Peter Singer (not Singer J), John Harris and David Price. I hope I can fairly say that they take an utilitarian view in that they countenance the consideration of whether the particular life is worth living. They would reject the idea that all lives have equal value. A new contribution to the debate is *End-of-Life Decisions in Medical Care*, 2012 by Stephen W. Smith who considers that it is important to examine the meaning of the word "life". He draws on Ronald Dworkin's *Life's Dominion* at pp. 82-83 where he provides two possible ways in which we might define life. The first way, which the ancient Greeks called *zoe*, is the physical or biological life, the second called *bios* means life as lived. In other words, as Dworkin says, the "actions, decisions, motives and events that compose what we now call a biography". So Smith concludes at p. 319:

> "Determining the value of life was also a complex rather than a simple method. I have argued that the conceptions generally used – vitalism, the Sanctity of Life and the Quality of Life – provide too simplistic a recognition of the ways in which our lives are valued. Our lives have value not simply because of the fact that we exist or because of the things we can do with that existence. Instead, we value our lives because of a combination of those two elements. Our existence matters in a number of crucial ways but that is not the only way in which our lives have meaning. Additionally, the ways in which we use our lives provide additional value to our mere existence and the biographical aspects of the way of our lives have value and meaning can be as important as, and sometimes even more important than, the fact of our existence."

49. This is all fascinating stuff but not the stuff to lengthen a judgment which is already too long. Our hands are, it seems to me, tied by authority that is binding upon us. Peter Jackson J concluded that in this case the quality of life was not "truly awful or non-existent". He is criticised by the

appellant for this, but I reject the criticism. What he was in effect finding was that life was not intolerable for DJ. Whether that conclusion was right or wrong on the facts of this case is one thing, but it seems to me to be clear on the authorities that he was fully entitled to have regard to the question of intolerability: see *Wyatt's* case where the court held at [76]:

> "In our view this supports the proposition that Hedley J was right to observe that the concept of "intolerable to the child" should not be seen as a gloss on, much less a supplementary test to, best interests, it is, as the judge observed, a valuable guide to the search for best interests in this kind of case."

Thus it seems to me that a judgment on whether life is intolerable is a judgment on the quality of that life. It must, therefore, play some part in the assessment of best interests (as does the worthwhileness of treatments) but only as one of the many circumstances to take into account. Viewed objectively, DJ's life in the first months of his time in hospital was tolerable enough to require that all these treatment be tried and even that they be tried again but sadly the stage was eventually reached, as the medical evidence accepted by the judge demonstrated, that DJ's life would become quite intolerable were he to suffer a further crisis leading to a further setback in his health. Were that to happen the risks and burdens of trying to keep him alive would be disproportionate to the diminishing opportunities for him to take pleasure from his family. Thus there was no longer the need to try, try and try again to restore him to the state he was bravely fighting to achieve.

50. It was for those reasons that I concluded on 21st December that it was in the best interests of DJ that it would be lawful to withhold treatment and that the declarations should be granted to that effect.

Lady Justice Arden:

51. I agree with the conclusion of Sir Alan Ward but I have arrived at this result by a different route.

52. I adopt with great gratitude Sir Alan Ward's comprehensive explanation of the background to this appeal and the submissions on it.

53. In making my decision as to the best interests of DJ, my approach is to start with his wishes. As I see it, section 4 of the Mental Capacity Act 2005 requires us to give great weight to the wishes of the individual: see, in particular, ss (4), (6) and (7), set out in paragraph 26 above.

54. These subsections are based on the recommendations of the Law Commission of England and Wales in its report on *Mental Incapacity* (Law Com No 231, (1995) paragraphs 3.26 to 3.36).

55. The Law Commission pointed out in its report that its recommendations involved a significant departure from the earlier case law, where the emphasis had been on whether the decision accorded with an accepted body of medical opinion. The Law Commission's view was that:

> "Decisions taken on behalf of a person lacking authority require a careful, focused consideration on that person as an individual."

56. Thus, while we must act on the basis of the medical evidence, it is not the only factor to be considered. Consideration of the wishes of the individual himself or herself, so far as they can be ascertained from the evidence, is an important part of the exercise of determining what is in an individual's best interests. Each individual is free to reach his or her own view, and have his or her own wishes, about the continuation of medical treatment.

57. It is similarly important to note that section 4(6)(a) requires the court to have regard to an individual's *present* wishes, and not just those expressed in the past. DJ shows signs of happiness when he recognises his family members around his bedside, and this shows that he (and others) derive value from his life. This is some indication of his present wishes as regards the continuation of treatment.

58. DJ has approached life-threatening illness before with enormous courage and determination. He has the great advantage of a devoted family and much to live for in that regard. The inference which I draw from the evidence is that he would wish his life to be saved by all reasonable means, and that he would not be concerned by reduced enjoyment of life due to disability or by being in a state of complete dependence on others.

59. If the court has any doubt as to an individual's wishes or as to whether treatment should be given, it should proceed on the basis that the individual would act as a reasonable individual would act.

60. There is no direct evidence about DJ's wishes about a situation like the present.

61. We are talking about treatment that involves a high degree of risk. The risk is not only that the treatment will not succeed. There are other risks such as the risk of injury, further infection, trauma and side effects that cannot be controlled. These matters may potentially significantly

increase the physical burdens which DJ already has to bear in his weak medical state. We are not talking about treatment that can be administered without difficulty, such as antibiotics; nor are we talking about basic human needs of nutrition and water.

62. DJ's medical condition is extreme. His ability to stave off death, which we must all face, is declining fast.

63. Acting with humanity, and with respect for DJ's autonomy, I consider in the light of DJ's medical condition, his wishes would be unlikely to be to have the treatment of the kind in issue here, and that a reasonable individual in the light of current scientific knowledge would reject it.

64. I agree with Sir Alan Ward for the reasons he gives that the treatment would be unduly burdensome for DJ, and not in DJ's best interests.

65. On the evidence I do not consider that there can be any real doubt about this conclusion.

66. I do not, however, consider that this case raises any legal issue in this case with respect to quality of life. Under the law, human life is sacrosanct, even that which is only partially enjoyed as in the case of DJ, with only diminished consciousness. DJ is not a child born without cognitive function, where different considerations might arise.

67. I have been greatly assisted by the judge's judgment, but I have reached a different conclusion in the light of further evidence. I have read that evidence with Mr Wise's submissions in mind.

68. I, too, wish to express my admiration for DJ's loyal and loving family. They have performed the important role, which the law recognises as being a proper one, of protecting DJ's interests in his time of great need.

69. I have written this judgment as if DJ had not passed away shortly after the hearing because that is the basis on which I came to my conclusions.

Lord Justice Laws:

70. I agree with the orders proposed by Sir Alan Ward, for the reasons given by him.